

## Complete Summary

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### GUIDELINE TITLE

Recommendations for end-of-life care in the intensive care unit: the Ethics Committee of the Society of Critical Care Medicine.

### BIBLIOGRAPHIC SOURCE(S)

Truog RD, Cist AF, Brackett SE, Burns JP, Curley MA, Danis M, DeVita MA, Rosenbaum SH, Rothenberg DM, Sprung CL, Webb SA, Wlody GS, Hurford WE. Recommendations for end-of-life care in the intensive care unit: the Ethics Committee of the Society of Critical Care Medicine. Crit Care Med 2001 Dec;29(12):2332-48. [127 references] [PubMed](#)

### GUIDELINE STATUS

This is the current release of the guideline.

## COMPLETE SUMMARY CONTENT

SCOPE  
 METHODOLOGY - including Rating Scheme and Cost Analysis  
 RECOMMENDATIONS  
 EVIDENCE SUPPORTING THE RECOMMENDATIONS  
 BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS  
 QUALIFYING STATEMENTS  
 IMPLEMENTATION OF THE GUIDELINE  
 INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT  
 CATEGORIES  
 IDENTIFYING INFORMATION AND AVAILABILITY  
 DISCLAIMER

## SCOPE

### DISEASE/CONDITION(S)

Conditions requiring end-of-life care in an intensive care unit (ICU)

### GUIDELINE CATEGORY

Counseling  
 Management

### CLINICAL SPECIALTY

Critical Care

## INTENDED USERS

Advanced Practice Nurses  
Physician Assistants  
Physicians

## GUIDELINE OBJECTIVE(S)

To provide information and advice for clinicians who deliver end-of-life care in intensive care units (ICUs)

## TARGET POPULATION

Patients in the intensive care unit (ICU) who are receiving end-of-life care

## INTERVENTIONS AND PRACTICES CONSIDERED

Palliative Care

General Management Strategies

1. Addressing patient needs
  - Receiving adequate pain and symptom management
  - Avoiding inappropriate prolongation of dying
  - Achieving a sense of control
  - Relieving burden
  - Strengthening relationships with loved ones
2. Addressing family needs in relation to the dying person
3. Addressing clinical team needs
4. Assessment of pain and suffering
  - Evaluation of level of consciousness and awareness
  - Assessment of breathing pattern
  - Assessment of hemodynamics
5. Notification of death
6. Obtaining permission for autopsy
7. Attending funerals
8. Referral of family to bereavement programs

Treatments

1. Nonpharmacologic approaches to pain and suffering
2. Pharmacologic approaches to pain and suffering
  - Opioids
    - Morphine
    - Hydromorphone
    - Fentanyl
    - Meperidine (considered, but not recommended)
  - Benzodiazepines
    - Lorazepam
    - Midazolam
  - Neuroleptics

- Haloperidol
  - Propofol
  - Barbiturates
    - Pentobarbital
3. Alleviation of specific symptoms
    - Positioning, oxygen, opioids, bronchodilators, or diuretics for relief of dyspnea
    - Anti-emetic agents or nasogastric drainage for relief of nausea and vomiting
    - Provision of food and fluid if desired by the patient
    - Attention to keeping the patient clean, dry, and free from odor for relief from skin ulceration
    - Antipyretics and antibiotics for patients with fever and infection
    - Pharmacologic management for relief of delirium
  4. Withdrawal of life-sustaining treatments
  5. Terminal extubation vs. terminal wean
  6. Terminal sedation
  7. Neuromuscular blocking agents (NMBAs)

#### MAJOR OUTCOMES CONSIDERED

- Signs and symptoms
- Pain

### METHODOLOGY

#### METHODS USED TO COLLECT/SELECT EVIDENCE

Searches of Electronic Databases

#### DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Not stated

#### NUMBER OF SOURCE DOCUMENTS

Not stated

#### METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus (Committee)

#### RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

#### METHODS USED TO ANALYZE THE EVIDENCE

Review  
Review of Published Meta-Analyses

#### DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

#### METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

#### DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

Not stated

#### RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

#### COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

#### METHOD OF GUIDELINE VALIDATION

Peer Review

#### DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Not applicable

### RECOMMENDATIONS

#### MAJOR RECOMMENDATIONS

##### Preparation of the Patient, the Family, and the Clinical Team

As the decision to forego further use of life-sustaining treatments is being made, the family and clinical team must be prepared for what is to follow. As familiar as many clinicians may be with the process of withdrawing life support, it is a singular event in the life of the patient and often is unprecedented for family members. Therefore, they may suffer great anxiety during the experience. Clear and explicit explanations on the part of the clinician may alleviate anxiety and refocus familial expectations.

##### Needs of the Patient

The health care team has an obligation to provide care that relieves suffering arising from physical, emotional, social, and spiritual sources. The patients in one study by Singer identified five domains of good end-of-life care: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones.

Most patients have already lost consciousness by the time life-sustaining treatments are removed. Some, however, such as those with cervical quadriplegia or amyotrophic lateral sclerosis, may be fully conscious. Whenever possible, patients should be prepared for the planned sequence of events and reassured about what they may experience.

Experience of hospice workers shows that the majority of dying patients fear pain and dyspnea. First and foremost, patients should be assured that management of their pain and distress will be the highest priority of their caregivers. Depending on personal preferences and spiritual considerations, some patients will want to be more sedated than others. Patients should understand, however, that the clinicians will take their cues from the patient and will try to tailor the administration of sedation and analgesia to the individual needs and desires of the patient.

Closely related is the need to assure patients that they will be treated with respect and dignity, both during and after the dying process. A policy that explicitly allows and encourages the continuous presence of family and friends at the bedside is one means of expressing this commitment. For patients who maintain relational capacity, the opportunity to say good-bye may be of paramount importance.

Patients should know that their cultural beliefs are understood and that cultural expectations will be met. Clinicians must plan ahead in this regard and be sure that they fully understand the relevant cultural expectations regarding the process of dying, the handling of the body after death, views about autopsy and organ donation, and cultural norms of grieving. Prior consultation with local representatives of cultural groups may be invaluable. Patients should be given every opportunity to experience spiritual meaning and fulfillment. Involvement of clergy will often be desirable, and performance of religious services and rites at the bedside should be encouraged. For children, cultural and spiritual observances should be oriented toward providing an age-appropriate understanding of dying, as well as providing the parents and family with meaningful rituals for coping with the death of a child.

### Needs of the Family

Although the needs of the patient must be the primary focus of caregivers, there is growing consensus that a family-centered approach is particularly important in end-of-life care. Families of the dying need to be kept informed about what to expect and about what is happening during the dying process. Communication between clinicians and grieving families may be difficult in the absence of a prior relationship, as is frequently the case in the intensive care unit (ICU). Primary care providers and other more familiar clinicians may be able to provide a helpful interface with the ICU team.

The needs of families have been assessed by a survey tool known as the Critical Care Family Needs Inventory. A meta-analysis of several studies that have used this tool identified the most important family needs, many of which focused on the desire to have ongoing communication with the health care team. Combining information from a number of studies leads to a summary of the needs of families, as seen below.

#### Ten Most Important Needs of Families of Critically Ill Dying Patients

1. To be with the person
2. To be helpful to the dying person
3. To be informed of the dying person's changing condition
4. To understand what is being done to the patient and why
5. To be assured of the patient's comfort
6. To be comforted
7. To ventilate emotions
8. To be assured that their decisions were right
9. To find meaning in the dying of their loved one
10. To be fed, hydrated, and rested

Families need the opportunity to be with the dying person. Although not always possible, a private room is the environment most conducive to emotional and physical intimacy and should be identified as a goal for excellent care of the dying (as well as a legitimate factor in justifying this cost to third-party payers). Usual restrictions on visitation should be relaxed as much as possible, especially with regard to restrictions on children (in some hospitals, even pets have been allowed for short visits). This also may mean accepting and tolerating large groups of family and friends at the bedside, which may be disconcerting to some clinicians. Whenever possible and within reason, withdrawal of life support should be timed to allow for the arrival of family members who must travel long distances. Not all families, however, want to be at the bedside at the time of the patient's death. Notifying the family that death is imminent should not be linked with an expectation that the family will be present. Families need to be reassured that it is also acceptable for them to remain at home.

Attention to detail can make an enormous difference. For example, providing the family with an electronic pager or cellular phone can allow them to break away for awhile without feeling out of contact. Clinicians can remind family members that they may want to contact clergy, friends, or others and can assist in making the calls if possible. Simple amenities like the presence of tissues, chairs, blankets, coffee, water, and a phone and general attention to the aesthetics of the room can contribute substantially to the family's sense of well-being and peacefulness. After the death of the patient, attention to detail may be greatly appreciated, as in freshly shaving the face of a man or clothing a child in her own pajamas.

Families vary in their tolerance for uncertainty and ambiguity, but clinicians, from the primary intensivist to the subspecialists to the nursing staff, should strive to deliver a consistent message. This may be facilitated by having all communication occur through the same person.

Families should clearly know the identity of the attending physician, understand that this person is ultimately responsible for the patient's care, and be assured of

his or her involvement. Clinicians should avoid making firm predictions about the patient's clinical course, because these are notoriously difficult to make, are often inaccurate, and may result in a substantial loss of credibility when they are in error. Although clinicians should be sensitive and compassionate in their communication, it is important that they explain the physiologic process of dying and describe in concrete terms how the patient will die and what it will look like. At times it will be necessary for the clinicians to anticipate, ask, and answer questions that the family appears to be afraid of or unable to verbalize. Families may benefit from reassurance that the clinicians are focused on the patient's comfort. Clinicians should earn the patient's and family's confidence by continually assessing the patient's suffering and demonstrating that pain-relieving medications and treatments are constantly available. Families should know that the caregivers are committed to having a presence at the bedside, even when the family members themselves are not able to be there. Finally, families often need to be reassured about the decisions they have already reached, emphasizing that the responsibility for these decisions is shared between the family and care team. This can help to dispel lingering doubts and potential feelings of guilt.

Families should have the opportunity to be helpful. They may be invited to participate in activities to relieve discomfort, such as mouth care, bathing, and repositioning. They should be encouraged to participate in assessment of the patient's pain and suffering. This is especially important in pediatrics and provides parents with an opportunity to express their nurturing role. Families also should be encouraged to bring in meaningful personal articles and be allowed to keep these articles at the patient's bedside.

Families should be encouraged to express their emotions. Both before and after the death of the patient, they should be given the opportunity to reflect on the patient's life and to recall shared memories. For neonates or young children, it may be necessary to create special memories through spiritual rituals or cultural tradition.

During the withdrawal of life support, all distractions should be eliminated so that the family's attention can be devoted entirely to the patient. In most cases, monitors should be turned off and the leads and cables should be removed from the patient. In some cases, catheters such as nasogastric tubes, urinary catheters, and arterial catheters also may be removed. In other situations, however, doing so may be more disruptive than beneficial. Even if there is the possibility that an autopsy may be required by the medical examiner, removal of catheters and tubes before death is not prohibited when this is done for the benefit of the patient and family (medical examiners may discourage or prohibit removal of lines and tubes after death, however). Bedrails can be lowered and restraints removed to allow family members more intimate contact with the patient. Although some family members may not desire to be at the bedside through the process of withdrawal, they should be given the opportunity to be present and possibly even to participate in the withdrawal of treatment. Finally, families should have private time to be with the patient after death and before removal of the body from the ICU.

Needs of the Clinical Team

Although all members of the clinical team should have active roles in providing end-of-life care, key aspects of this care should be performed and modeled by respected clinicians with leadership roles in the institution. These individuals are in a unique position to reinforce the message that excellent care at the end of life is an institutional priority. Attendings should affirm their leadership by personally supervising critical aspects of this care. For example, only 64% of Society of Critical Care Medicine (SCCM) physician members who perform extubation at the end of life remove the endotracheal tube themselves; the remainder presumably leave this task to nurses and respiratory therapists. Although removal of an endotracheal tube is clearly not a technically challenging procedure, personal involvement of the attending during this transitional event can send a powerful message about the importance of end-of-life care.

The clinical team needs to be multidisciplinary and committed to cooperation and clear communication. A recent survey pointed to difficulties in this area, with critical care nurses reportedly needing to engage in many covert practices that were in conflict with the physician's orders. These included administering more opioid than ordered and concealing the action by falsifying the amount "wasted," increasing doses of opioids when patients were already comatose, or only pretending to administer life-sustaining treatments that were ordered, such as by substituting saline for a vasopressor infusion. The methodology of this study has been harshly criticized, and many doubt that it represents an accurate picture of current critical care practices. Nevertheless, it does suggest that nurses are concerned about the overuse of life-sustaining technology and the unresponsiveness of physicians to address this concern as well as the patients' pain and suffering. These concerns emphasize the need to develop a better consensus between physicians and nurses regarding the goals and strategies for providing end-of-life care in the ICU.

The survey also pointed to the need for better education about end-of-life care and an institutional commitment to maintaining clinical competence. This is aided by providing clinicians with opportunities to gain knowledge concerning intensive palliative care. This education should focus on how to support and counsel families through the withdrawal process, ensure respect for various religious and cultural beliefs, and emphasize general communication and teamwork skills. Educational efforts need to be ongoing so that new staff are continually oriented to these competencies.

Clinical teams need administrative support. This begins by affirming the value of intensive palliative care at the highest levels of the institution and continues with protecting nursing staff from increased workloads when they are involved in delivering time-intensive palliative care. Administrators also can support intensive palliative care by allowing clinicians to minimize transfers of dying patients from the ICU to unfamiliar staff and locations, unless this is in the best interests of the patient and family.

Clinical teams need to have opportunities for bereavement and debriefing. One option is to have regularly scheduled meetings where staff can share their thoughts and experiences as well as critique the quality of the care they provided. This can be an opportunity to assess whether the patient experienced a "good death" and to discuss what went well and what could have gone better. These meetings also can be a forum for organizing a structured bereavement program



that may include sympathy cards, follow-up phone calls, or distribution of educational materials to help guide families through the grieving process.

### Ensuring the Comfort of the Patient

Intensive care medicine is so thoroughly grounded in the curative model of care that clinicians may have a difficult time "switching gears" and adopting a model focused primarily on symptomatology. An important difference between these models is the criteria used to determine whether a particular monitor, diagnostic test, or therapeutic intervention is indicated. In the curative model, the criteria are related to the degree to which the procedure will contribute to the patient's recovery from illness. In the palliative model, the criteria are related to whether the intervention will improve symptom relief, improve functional status, or ameliorate emotional, psychological, or spiritual concerns. Only interventions that are favorable in this analysis should be used.

The transition from the curative to the palliative model often occurs in a piecemeal fashion. Sometimes the patient may receive an inconsistent combination of therapies, some aimed at comfort and some aimed at cure. One practical solution for dealing with this problem is to completely rewrite the patient's orders and care plan, just as if the patient were being newly admitted to the ICU. Each monitor, test, or intervention should be evaluated in terms of the degree to which it furthers the patient's goals before it is entered onto the order sheet. Some routine procedures that usually are considered an intrinsic part of ICU care, such as measuring vital signs, performing routine laboratory tests and chest radiographs, and endotracheal suctioning, may not contribute positively to the patient's comfort and should be excluded. On the other hand, some therapeutic procedures, such as the intravenous infusion of vasopressors or inotropes, may cause very little discomfort (requiring only the maintenance of intravenous access) but may substantially benefit the patient by maintaining perfusion of vital organs, thereby improving level of consciousness, renal and liver function, and gastrointestinal absorption. In some circumstances, such therapy might be reasonable, even in a terminally ill patient who is not receiving other life-prolonging therapies.

One caveat to this approach is that clinicians must interpret the goals of treatment from the perspective of the patient. For example, one study found that many cystic fibrosis patients were still taking vitamins on their last day of life, well after the point at which it was clear that they were very near death. Certainly the vitamins were not providing any "medical" benefit at this point, yet the authors surmised that the vitamins may have been part of a routine of care that the patient found comforting, and that altering this pattern or ritual of care as the patient approached death would have caused more distress than comfort. In this sense, then, some treatments may be indicated because of the psychological benefits (rather than strictly medical benefits) that they confer on the patient.

In most cases, however, rewriting the orders at the time that the goals of care are revised should reduce the use of monitors, tests, and procedures.

### Assessment of Pain

Many patients die with treatable pain, even in intensive care units. One probable reason for this is the strong bias in medicine toward the treatment of diseases rather than symptoms (e.g., the treatment for the acute abdominal pain of appendicitis is surgery, not morphine). Palliative care reverses these priorities and places symptom management ahead of diagnosis and definitive treatment. Another reason why pain is inadequately recognized and treated is because it is inherently subjective (e.g., "pain is whatever the patient says it is") and difficult to measure. Palliative care gives pain relief a high priority. The concept of pain as the "fifth vital sign" is one way of emphasizing the importance of treating pain assessment as a core element of patient care. The increased use of pain scales has provided for better quantification of the patient's experience. Unfortunately, pain scales may be better suited to postoperative and other forms of acute pain than they are to the chronic pain frequently experienced by dying patients.

Assessment of pain in dying patients often relies primarily on evaluation of level of consciousness and awareness, breathing pattern, and hemodynamics. Consciousness can be assessed by the patient's response to stimuli, by the patient's agitation or motor activity, and by facial expression. Bispectral analysis, which uses a processed electroencephalographic signal to assess a patient's level of consciousness, has been used as an adjunctive monitor for assessing patient comfort during the withdrawal of life support. Although this approach to pain assessment is at odds with the goal of reducing intrusive technology and monitoring at the end of life, in very rare circumstances it may have a role when assessment of distress is particularly difficult, such as in patients who are receiving neuromuscular blocking agents (see subsequent discussion).

Assessment of breathing patterns can be complicated in dying patients. Irregular breathing patterns are a natural part of dying and may not be uncomfortable for the patient. Unfortunately, the irregular pattern that accompanies dying is often referred to as "agonal," which may imply to the family and other clinicians that the patient is in "agony." Gasping is a medullary reflex and can occur in the absence of consciousness. Similarly, noisy respirations from airway secretions (the "death rattle") are more likely to be distressing to the family and other observers than they are to the patient. The question of whether clinicians should ever treat the patient primarily to relieve the distress of the family is considered subsequently.

The hemodynamic status of the patient (e.g., heart rate and blood pressure) is an unreliable indicator of pain, because tachycardia and hypertension can occur even in the absence of consciousness. Such hemodynamic signs may be more indicative of distress when they occur as part of a constellation of autonomic signs such as diaphoresis or lacrimation or when they occur in association with noxious stimuli.

The assessment of pain in neonates and small infants deserves special comment. Until recently, many clinicians believed that these patients had diminished capacity to experience pain and suffering and that they were more prone to serious side effects from the use of potent analgesic and anesthetic medications. Recent studies suggest, however, that pain pathways are functional from late gestation onward, and advances in anesthesiology and pediatrics have resulted in the development of safe anesthetic regimens and pain treatment protocols for patients of all ages. These insights extend the same emphasis on relief of pain

and suffering that has become mandatory for adults to the clinical management of dying newborns and children.

### Assessment of Suffering

"Pain" and "suffering" are not synonymous, but neither are they inherently distinct. In addition to its neurobiologic dimensions, pain also has powerful psychological and cultural components. Suffering is a more global term and includes consideration of the existential pain that is an essential part of the human condition. Some have argued that clinicians tend to be biased toward reductionistic interpretations of pain and suffering and often fail to attend to the broader and more difficult issues that may be of much greater importance to patients and families. The fact that there are not yet validated "suffering scales" does not diminish the importance of this dimension of the dying process.

Suffering may have profound meanings for patients that are unrelated to physical symptoms. Some patients, for example, may find redemptive meaning in their suffering and therefore may not want to avoid it entirely. By seeking to understand and appreciate these meanings, clinicians can individualize their care in ways that are responsive to these varying perspectives.

### Nonpharmacologic Approaches to Pain and Suffering

"Dying in one's sleep" has always been viewed as a natural way to depart from this life. There are many physiologic reasons to support this view. Respiratory depression during dying may produce hypercarbia and hypoxia. Studies of alveolar anoxia suggest that the most rapid descent into unconsciousness with the least agitation occurs when hypoxia is allowed to progress in the face of normocarbia, a finding that could have relevance for approaches to ventilator withdrawal (see subsequent discussion).

As cardiac activity decreases, hypoperfusion will decrease cerebral function. Decreased oral intake will lead to dehydration and a similar decrease in cerebral function. "Starvation euphoria" is a recognized phenomenon, possibly related to endogenous opioid production or the analgesic effects of ketosis. Table 2 of the original guideline document summarizes the physiologic effects that accompany the foregoing of specific therapies and illustrates some of the ways that the withdrawal of treatments may actually contribute positively to the patient's comfort. Although these physiologic effects probably contribute to the comfort of dying patients, they are not uniformly effective. Some may make the patient more uncomfortable before the patient's consciousness diminishes. Accordingly, these physiologic effects should be attenuated by other measures.

Environmental factors can play an important role in promoting the patient's comfort. As noted previously, there are pros and cons to having dying patients remain in the ICU. The advantages include continuity of care and the greater availability of nurses and physicians. The benefits of leaving the ICU may include return to a more familiar (and possibly more private) setting, as well as less technology and cost. In either location, much can be done to enhance the patient's comfort, such as providing privacy and a comfortable bed, reducing lighting and noise, removing restraints, eliminating unnecessary monitors and machines, and providing the space and opportunity for interaction with the

patient's family and loved ones. Beyond these simple measures, there may be cultural or spiritual factors, such as the opportunity for ritual, prayer, or music that can increase the patient's comfort.

## Opioids

Opioids have been a mainstay for the treatment of pain and suffering in dying patients (refer to table 3 of the original document guideline for dosing information). Opiates are mu-receptor agonists, and central mu-receptors invoke analgesia, sedation, respiratory depression, constipation, urinary retention, nausea, and euphoria. Vasodilation may produce hypotension but also can have a therapeutic effect by decreasing venous return to the right heart, thereby decreasing filling pressures and relieving cardiogenic pulmonary edema. Practice parameters from the Society of Critical Care Medicine (SCCM) cite morphine as the preferred analgesic agent in the ICU, with hydromorphone and fentanyl as alternative agents.

Morphine is the most frequently used opioid analgesic in the United States, mainly because of its low cost, potency, analgesic efficacy, and euphoric effect. It has a half-life of 1.5 to 2 hrs in normal subjects after intravenous administration, but the elimination half-life may be prolonged in patients with hepatic or renal dysfunction. Although allergic reactions to morphine have been reported, it is much more common for allergic symptoms to be related to histamine release, especially when the medication is administered rapidly.

Fentanyl is a synthetic opiate with 80 to 100 times the potency of morphine. Fentanyl does not cause histamine release, which may explain the reduced incidence of hypotension compared with morphine. It has less sedative and euphoric effects compared with morphine. It has a half-life of 30 to 60 minutes because of rapid redistribution, but with prolonged administration the elimination half-life increases to 9 to 16 hours, as the peripheral sites of redistribution become saturated. Because both fentanyl and morphine reach 90% of their peak effect within 5 minutes of intravenous administration, these medications can be safely redosed at 5-minute intervals. Hydromorphone is a semisynthetic morphine derivative, similar to morphine but with more potent analgesic and sedative properties and significantly less euphoria.

The SCCM practice parameters recommend against the routine use of meperidine. Normeperidine is an active metabolite of meperidine that produces signs of central nervous system excitation such as apprehension, tremors, and/or seizures, especially in patients with renal insufficiency. The Agency for Healthcare Research and Quality (formerly the Agency for Health Care Policy and Research) has recommended that meperidine should not be used except for a brief course of treatment in otherwise healthy patients who have demonstrated an unusual reaction or allergic response to morphine (meperidine does not cross-react in morphine allergy).

When intravenous access is either not possible or not desired, alternative routes of administration should be considered, including oral, rectal, subcutaneous, and transdermal. Long-acting formulations of several opioids are also available. Because most patients dying in ICUs have intravenous access, and because these

alternatives are extensively discussed in the palliative care literature, these other options for treatment are not reviewed here.

## Benzodiazepines

Benzodiazepines reduce anxiety and cause amnesia, important in preventing recall or breakthrough suffering. In addition to having a desirable synergistic sedative effect with opioids, benzodiazepines are anticonvulsants and may help prevent the development of premorbid seizures.

Lorazepam is an intermediate-acting benzodiazepine that has a peak effect approximately 30 min after intravenous administration. In adults, elimination is not altered by renal or hepatic dysfunction. The recommended starting dose is about 0.05 mg/kg every 2 to 4 hours when administered by intermittent bolus.

Midazolam is a short-acting benzodiazepine. Because it is water soluble, it is not painful on peripheral injection. After intravenous administration, it undergoes a structural change to a lipophilic compound that rapidly penetrates the central nervous system and gives it an onset of action comparable to diazepam. It has a brief duration of action attributable to rapid redistribution, however, and administration by continuous infusion often is required for the medication to have a sustained effect. Starting doses for adults are 1 mg intravenously or 1 to 5 mg/hr by continuous infusion. Starting doses for children are 0.1 mg/kg intravenously or 0.05 to 0.10 mg·kg<sup>-1</sup>·hr<sup>-1</sup>.

## Neuroleptics

Neuroleptics may be effective when the patient is manifesting signs and symptoms of delirium. Delirium is an acute confusional state that can be difficult to differentiate from anxiety, yet the distinction is important, because the administration of opioids or benzodiazepines as initial treatment for delirium can worsen the symptoms. Haloperidol has proven efficacy in the management of delirium. Although the drug does not possess a significant sedative effect, patients whose delirium is ameliorated by haloperidol often require less sedation with other agents. In addition, in one study this agent was used at least occasionally as an adjunct to the discontinuation of life-sustaining measures by 24% of physicians.

Starting doses of haloperidol in adults range from 0.5 to 20 mg, depending on the severity of the patient's delirium. Additional doses should be titrated at 30-min intervals until the patient's symptoms are controlled. Doses up to 50 or 60 mg may be required. Once delirium is controlled, patients often can be maintained on 50% to 100% of this amount in divided doses over 24 hours. Haloperidol also has been administered successfully by continuous infusion, at doses ranging from 3 to 25 mg/hr.

Disadvantages of haloperidol include extrapyramidal symptoms, which are less common when the drug is given intravenously as opposed to enterally. Extrapyramidal symptoms are more common in children, reducing the usefulness of this medication in the pediatric population.

## Propofol

Propofol is a sedative and anesthetic agent that is attractive primarily because of its short half-life. In most studies of ICU sedation, it has had a comparable effect to a continuous infusion of midazolam. Low doses can be titrated to achieve varying planes of sedation or unconsciousness. A typical starting dose of propofol for both adults and children is 1 mg/kg, but some patients may become hypotensive with even this much, emphasizing the need to titrate to effect. When administered by infusion, a typical starting dose is  $0.5 \text{ mg} \cdot \text{kg}^{-1} \cdot \text{hr}^{-1}$ , with most patients requiring between 0.5 and  $3.0 \text{ mg} \cdot \text{kg}^{-1} \cdot \text{hr}^{-1}$ . The potential for drug incompatibility is a problem with propofol, because it requires that propofol be administered through a dedicated intravenous catheter. In addition, because of the potential for contamination and infection, the manufacturer recommends that propofol infusion bottles and tubing be changed every 12 hours and that solutions transferred from the original container be discarded every 6 hours. Like diazepam, propofol is painful when administered via a peripheral vein.

## Barbiturates

Barbiturates have both advantages and disadvantages when used at the end of life. Their disadvantages include an absence of analgesic effect, necessitating the concurrent administration of analgesics (e.g., opioids) whenever the patient's symptoms include pain. Barbiturates also have been strongly linked to the practice of euthanasia, having been used for that purpose in the Netherlands and for the execution of prisoners by lethal injection in the United States. Even when appropriately administered within existing guidelines, therefore, their use could be misinterpreted as the practice of euthanasia. Advantages of barbiturates include their ability to reliably and rapidly cause unconsciousness, which may be necessary for the rare patient whose pain does not respond to any other approach. In addition, because their mechanism of action differs from the opioids and benzodiazepines, they may be useful in patients who have developed extreme levels of tolerance to these other medications. On balance, although barbiturates are very helpful in limited circumstances, they are not in the first line of medications that should be used in treating the terminally ill. Propofol offers many of the same advantages as the barbiturates without the complicating features. A typical starting dose for pentobarbital, a barbiturate with a medium duration of action, is 150 mg intravenously for adults and 2 to 6 mg/kg intravenously for children. For prolonged effect, the medication may be continued in doses of 3 to  $5 \text{ mg} \cdot \text{kg}^{-1} \cdot \text{hr}^{-1}$ . Because tolerance develops rapidly, progressive escalation of the dose is often necessary. These adjunctive agents are summarized in Table 4 of the original guideline document.

## Principles for Dosing and Titration

Although starting doses for sedation and analgesia were discussed previously and included in the tables, in many cases these doses will be irrelevant, because most patients will have already received these agents and will have already developed some tolerance to their effects at the time of withdrawal of life support. These agents should be titrated to effect, and the dose should not be limited solely on the basis of "recommended" or "suggested" maximal doses. In most cases, patients who do not respond to a given dose of an opioid or benzodiazepine will respond if the dose is increased - there is no theoretical or practical maximal dose. In rare cases, this generalization does not hold; in these patients, alternative classes of agents (like barbiturates or propofol) should be considered.

Current ethical and legal guidelines place importance on the intentions of clinicians in administering analgesics and sedatives at the end of life. Specifically, clinicians should administer doses that are intended to relieve pain and suffering but not intended to directly cause death. Because intentions are essentially subjective and private, the only ways to infer the nature of an individual's intentions are by self-report and by an analysis of his or her actions. Accordingly, documentation of one's intentions in the patient's chart is an important part of providing end-of-life care. When "p.r.n." (that is, "as needed") orders are written for analgesics and sedatives, the indication for administration should be stated clearly (e.g., pain, anxiety, shortness of breath). This reduces the likelihood of misinterpretation or abuse. With regard to actions, when a clinician titrates morphine in doses of 1, 5, or 10 mg every 10 or 20 minutes, it is plausible to conclude that the clinician intends to make the patient comfortable and not to directly cause the patient's death. On the other hand, when a clinician administers 2 g of morphine acutely to a patient who is not profoundly tolerant, it is difficult not to conclude that the clinician did intend the death of the patient.

The concept of "anticipatory dosing" (as opposed to reactive dosing) also should guide clinicians in the use of sedation and analgesia at the end of life. The rapid withdrawal of mechanical ventilation is an example of the need for anticipatory dosing. At the time of ventilator withdrawal, the clinician can anticipate that there will be a sudden increase in dyspnea. It is not sufficient simply to respond to this distress with titrated doses of an opioid (reactive dosing). Rather, clinicians should anticipate this sudden event and provide adequate medication beforehand (anticipatory dosing). As a general rule, the doses of medication that the patient has been receiving hourly should be increased by two- or three-fold and administered acutely before withdrawing mechanical ventilation.

Please refer to the original guideline document for data on the use of sedatives and opioids during the withdrawal of life support.

### Alleviation of Specific Symptoms

Dyspnea is a form of suffering and is probably the most important symptom that must be relieved for patients dying in the ICU. The incidence of this problem is not well described, but data suggest that it is present in up to half of dying persons. Although dyspnea in patients dying of respiratory failure is almost always attributable to progression of their underlying disease, clinicians should remember that the differential diagnosis for dyspnea is extensive and includes many potentially treatable conditions such as reactive airway disease, infection, pneumothorax, congestive heart failure, and anxiety. The response to this sensation is both physiologic (e.g., tachycardia, tachypnea) and psychological (e.g., panic, anxiety, fear). Assessment should include an investigation for potentially treatable causes before focusing on symptom management. Symptom severity scales, such as the modified Borg dyspnea scale and the Bizek agitation scale, can be used to assess symptoms associated with breathlessness.

Treatment of dyspnea may include pharmacologic and nonpharmacologic strategies. Simple positioning may be effective. Patients with chronic obstructive pulmonary disease may be most comfortable sitting up or leaning over a bedside table. Patients with unilateral lung disease (e.g., pneumonia) may prefer lying on one side more than the other. Pharmacologic approaches to dyspnea are varied.

Oxygen may enhance patient comfort by relieving hypoxemia. However, one study of advanced cancer patients reported that oxygen was no better than air in relieving dyspnea. Sometimes patients experience symptomatic relief by having air from a fan blowing gently on their face and may have increased dyspnea from a feeling of claustrophobia associated with the administration of oxygen by a facemask. Opioids relieve dyspnea by depressing respiratory drive, producing sedation and euphoria, and causing vasodilation, which can reduce pulmonary vascular congestion. Patients also may benefit from the judicious use of bronchodilators and diuretics to relieve small airway obstruction and pulmonary vascular congestion.

Nausea and vomiting are frequently reported at the end of life. As with dyspnea, potentially treatable causes should be investigated before resorting to symptomatic management. Most nausea and vomiting can be controlled with anti-emetic agents. Although nasogastric drainage is sometimes effective for relief from profound ileus or small bowel obstruction, it may be more uncomfortable for the patient than occasional emesis.

Hunger and thirst are problematic concerns at the end of life. Some believe that the dying should always be given food and fluids and that this is a basic expression of our humanity and capacity for compassion. On this view, some caregivers believe that hunger and thirst should always be treated and encourage placement of nasogastric or gastrostomy tubes in terminally ill patients to administer nutrition when patients are no longer capable of oral sustenance. Current palliative care practices, however, recognize that loss of hunger and thirst are normal physiologic responses to the dying process, and that forced nutrition and hydration in this setting not only prolong the dying process but do not contribute to the patient's comfort. In addition, the metabolic abnormalities associated with dehydration tend to contribute to sedation and diminished consciousness rather than cause distress. Although the symbolism associated with providing food and fluid should not be dismissed lightly, the majority view in the United States now holds that food and fluid should be provided if they are desired by the patient and contribute to the patient's comfort; otherwise, they may be foregone.

Skin ulceration may be caused by local tissue conditions, infection, or ischemia from hypoperfusion and localized pressure or edema. Even the best skin care regimens are unlikely to promote healing under these conditions. The frequent turning and dressing changes that are required can cause more pain and discomfort than benefit. Attention to keeping the patient clean, dry, and free from odor may be the best goal under some circumstances.

Fevers and infections frequently occur in critically ill and dying patients. Because fever can be quite uncomfortable, antipyretics generally should be used. External cooling with ice packs, cooling blankets, or alcohol baths may create greater distress for the patient than the fever itself. Antibiotics may offer more benefit than burden for painful infections, such as otitis media, oral candidiasis, or herpetic infections.

Anxiety and delirium often occur at the end of life. The use of physical restraints should be avoided whenever possible. Pharmacologic management should be



gauged more toward the patient's comfort and peacefulness rather than toward resolution of the delirium.

### Withdrawal of Life-Sustaining Treatments

The indications for any proposed intervention in a dying patient should be assessed in terms of the goals of the patient. Any intervention that does not advance the patient's goals should be eliminated. This simple advice is persuasive in concept yet difficult to follow. In reality, physicians have many biases and preferences regarding the withdrawal of life-sustaining therapies that do not seem to be related to the needs or values of the patient. For example, a 1992 survey of SCCM physicians found that 15% almost never withdraw mechanical ventilation and that internists and pediatricians were more likely to withdraw mechanical ventilation than surgeons or anesthesiologists. Unless these differences were attributable to underlying systematic differences in the patient populations they cared for, the origins of these variations in practice must rest primarily with the preferences of the physicians themselves.

Some of these preferences are related to culture and religious beliefs. Some Jewish clinicians, for example, have religious reasons for believing that the withdrawal of life-sustaining treatments is "killing" and therefore is prohibited. In addition to these differences based on culture or religion, one study reported that physicians prefer to withdraw therapy supporting organs that failed for natural vs. iatrogenic reasons, to withdraw recently instituted vs. longstanding interventions, to withdraw therapies leading to immediate death rather than delayed death, but to withdraw therapies leading to delayed death when faced with diagnostic uncertainty. There were also patterns in the preferences of physicians for the order in which treatments were withdrawn: first being blood products, followed by hemodialysis, vasopressors, mechanical ventilation, total parenteral nutrition, antibiotics, intravenous fluids, and finally tube feedings. There was an underlying trend toward earlier withdrawal of treatments perceived as more artificial, scarce, or expensive. Specialists have also been reported to prefer to withdraw the therapy with which they are most familiar; for example, pulmonologists withdraw mechanical ventilation, nephrologists withdraw dialysis, and so forth. Decisions in pediatrics are also stereotyped, with deaths in most series almost always following the withholding or withdrawal of either mechanical ventilation or extracorporeal membrane oxygenation.

In light of these (perhaps unconscious) biases, it is useful to review the wide range of life-sustaining treatments that are used in critical care medicine and to work toward an approach that is less centered on physician preferences and more focused on the unique situation and needs of the patient. Table 5 of the original guideline document catalogs the types of life-sustaining treatments that may be withdrawn and illustrates the range of therapies that may be foregone, from measuring and recording vital signs to extracorporeal membrane oxygenation.

### Terminal Extubation vs. Terminal Wean

Although the early literature recommended blood gas monitoring during the withdrawal of ventilation, virtually all now agree that neither this nor noninvasive forms of respiratory monitoring are consistent with the palliative goals of promoting the patient's comfort and reducing technology whenever possible.

One recommended approach, commonly referred to as "terminal extubation," involves removal of the endotracheal tube, usually after the administration of boluses of sedatives and/or analgesics. The second technique, known as a "terminal wean," is performed by gradually reducing the FIO<sub>2</sub> and/or the mandatory ventilator rate, leading to the progressive development of hypoxemia and hypercarbia. In the latter technique there is considerable variability in the pace of the process, with some completing the wean over several minutes and others stretching it over several days.

The preferred approach varies widely. A 1992 survey of SCCM physicians found that 33% preferred terminal weaning, 13% preferred extubation, and the remainder used both. These preferences were correlated with specialty: Surgeons and anesthesiologists were more likely to use terminal weaning, whereas internists and pediatricians were more likely to use extubation ( $p < .0001$ ).

The principle advantage of the terminal wean is that patients do not develop any signs of upper airway obstruction during the withdrawal of ventilation. They therefore do not develop distress from either stridor or oral secretions, and if the wean is performed slowly with the administration of sedatives and analgesics, they do not develop symptoms of acute air hunger. These advantages not only promote the comfort of the patient but reduce the anxiety of family and caregivers.

Another cited advantage of terminal weans is that they are perceived to diminish the moral burden of the family and caregivers, presumably because the terminal wean is perceived as being less "active" than terminal extubation. Whether this is an advantage or disadvantage remains controversial. There is a risk that terminal weans may be perceived by families as bona fide attempts to have the patient successfully survive separation from the ventilator, even when this is not the expectation or intent of the clinicians - particularly when the wean is prolonged over several days. Terminal weans therefore should not be adopted as a means of avoiding difficult conversations with families about the patient's condition and prognosis.

In contrast to terminal weans, terminal extubations have the principal advantages that they do not prolong the dying process and that they allow the patient to be free from an "unnatural" endotracheal tube. The process of terminal extubation also is morally transparent; the intentions of the clinicians are clear, and the process cannot be confused with a therapeutic wean.

Although these two concepts have become fairly well entrenched into the lexicon of critical care medicine, the guideline developers believe that the terminology of terminal weans and terminal extubations is confusing and should be replaced by more specific descriptions of the process. The use of the word terminal suggests that withdrawal will directly result in death of the patient. Occasionally, however, patients who are separated from the ventilator with the expectation of failure survive to be discharged from the intensive care unit or the hospital. Weaning generally refers to a therapeutic procedure that occurs when patients are improving and expected to survive. It may be unclear whether the process includes removal of the artificial airway, supplemental oxygen, or positive pressure ventilation. The guideline developers believe it is preferable to use specific terms and to consider each of these therapies separately. An artificial

airway may be removed (extubation), the patient may have supplemental oxygen discontinued, and/or positive pressure ventilation may be reduced or eliminated. These approaches are not mutually exclusive. For example, withdrawal of the artificial airway may occur simultaneously with the withdrawal of oxygenation and ventilation (terminal extubation). Ventilation and oxygenation also may be withdrawn rapidly (by transitioning to a T-piece) or slowly (by gradually reducing the FIO<sub>2</sub> and/or ventilator rate). Then, as the patient's pharmacologic sedation is supplemented by the effects of hypoventilation and hypoxia, the artificial airway may be withdrawn. It is conceivable that each therapy (artificial airway, supplemental oxygenation, and mechanical ventilation) may be continued or eliminated, depending on the specific circumstances of the patient. In this way, decisions can be made more specifically and deliberately than when the choices are only between terminal wean and terminal extubation.

Finally, the method of withdrawal has important implications for the administration of sedation and analgesia. Abrupt changes in the patient's level of distress require the administration of anticipatory doses of analgesics and sedatives. If the decision is made to rapidly withdraw the artificial airway (extubation) or mechanical ventilation (transition to T-piece), for example, the patient generally should receive medication before the withdrawal in anticipation of distress, with subsequent doses titrated to the patient's level of comfort.

### Withdrawal Prototypes

No two instances of the withdrawal of life support are ever identical, yet certain prototypes have a number of features in common. They depend on the clinical characteristics of the patient and the type of life support that is being withdrawn. These were discussed in more detail by Campbell.

#### Ventilator Withdrawal from Patients Declared Brain Dead

Patients who have been declared brain dead are dead. Removal of the ventilator is not the withdrawal of life support, because the ventilator is not supporting life. The most straightforward approach to withdrawal of the ventilator in these circumstances is rapid removal of the artificial airway, oxygenation, and ventilation.

Clinicians should be aware, however, that brain dead patients may rarely exhibit dramatic movements, caused by the firing of spinal motor neurons that are known as the Lazarus sign. Such movements generally occur either during the apnea test or after the withdrawal of mechanical ventilation and are thought to be related to acute effects of hypoxia or ischemia on spinal motor neurons. The movements can be as extensive and complex as the patient sitting up in bed. Because current brain death criteria do not require the loss of all spinal activity, these movements do not exclude the diagnosis of brain death. If the patient's family is to be at the bedside during either the apnea test or the withdrawal of mechanical ventilation, it is imperative that the clinicians prepare them for what they might see, so as not to alarm them with the fear that the diagnosis of brain death might have been in error.

#### Ventilator Withdrawal from Unconscious Patients Unlikely to Experience Distress

This prototype includes patients who are comatose but who are not brain dead. Although patients who are truly comatose are not capable of experiencing anything, in some cases there may be doubt about whether the patient has any rudimentary capacity for experiencing pain or suffering. In these cases, clinicians should err on the side of caution and provide an appropriate level of analgesia and sedation.

Withdrawal of life support usually can proceed rapidly in such cases, either by withdrawal of the artificial airway or by removing the mechanical ventilator. In either case, the patient may require anticipatory dosing with analgesics and/or sedatives and may require additional medication administered as necessary, titrated to the observed level of the patient's distress. Because some unconscious patients will not require the administration of any additional sedatives or analgesics, however, these should be given on an individualized basis according to need rather than dosed according to protocol.

#### Ventilator Withdrawal from the Conscious or Semiconscious Patient Likely to Experience Distress

This prototype includes patients who are definitely able to experience suffering, and the method of withdrawal needs to be tailored to minimize distress. In most cases, this will involve a more gradual withdrawal of both ventilator rate and supplemental oxygen. Although there is indirect evidence that patients may be more comfortable when supplemental oxygen is removed before ventilator rate, there are no clinical studies to support this approach. In any case, the gradual withdrawal of ventilator support allows clinicians the opportunity to carefully titrate sedatives and analgesics to the patient's level of comfort, thereby ensuring that the patient does not experience any treatable pain or suffering. Once the patient has lost consciousness from the combined effect of the medications and hypoxia, then the artificial airway can be removed.

In some cases, such as those involving patients with cervical quadriplegia or those undergoing advanced life support, the patient may prefer the rapid withdrawal of ventilation while sedated to a sufficient depth to eliminate any possibility of dyspnea or air hunger. This approach is also acceptable but requires very close attention to the adequacy of the anticipatory dosing to make sure that the patient does not experience acute suffering at the time of ventilator withdrawal. One technique for ensuring this is to use rapidly acting medications such as thiopental or propofol in sufficient doses to relieve the patient's suffering.

#### Special Issues in Communicating with Families Near the Time of Death

##### Notification of Death

Breaking bad news is one of the most difficult tasks that physicians face but is a common necessity in the practice of critical care medicine. Little empirical research on this topic exists to ground recommendations; however, and most suggestions are therefore based primarily on common sense, experience, and intuition. These deficiencies may explain in part why few clinicians have received formal training in how to deliver bad news. Even so, certain principles can be recommended. Bad news should be delivered in person, whenever possible. The ideal location is in a private room that has seating available for everyone.

Clinicians should be attentive to their appearance, especially if they appear disheveled from performing a resuscitation or other work in the ICU. They should learn how to demonstrate compassion and empathy, by beginning with words of condolence, maintaining eye contact, and extending a comforting touch when appropriate. Although well-intended, clichés like "He's at peace now," or "At least she lived a long and happy life" should be avoided, because these are often not well received and can be seen as offensive.

Clinicians often inadvertently use unfamiliar jargon when talking with patients and families. Words such as code, CPR, and vent should be avoided in favor of more clearly understood terms such as heart stopped, tried to start the heart, and breathing machine. In particular, clinicians should not be afraid to use the words died and death; saying only that resuscitation was unsuccessful or that the patient expired will often risk misunderstanding. Development of these "bilingual" skills should be a priority for critical care clinicians.

The family frequently must be contacted by telephone if they are not present at the time of death. A Gallup poll of a sample of the U.S. adult population reported that when death of a family member was unexpected, most (64%) preferred to be told that the patient was critically ill and to come to the hospital immediately. Only 26% preferred to be told over the telephone that the patient had died. These findings were mirrored in a companion survey of physician practices, which found that 72% of the physicians preferred to defer informing the family of the patient's death until the family arrived at the hospital, whereas only 25% would relay the information immediately over the telephone. These preferences changed dramatically, however, when the death of the patient was perceived as "expected." In these circumstances, only 13% of physicians would delay notification until the family's arrival, with 83% informing the family directly.

When the patient has been declared dead by neurologic criteria ("brain dead"), clinicians must be particularly careful with their words so as not to confuse the family. One of the most common mistakes is to say something like, "We have diagnosed your son as brain dead. He will die very quickly after he is removed from the ventilator." Patients are declared dead at the time that the requirements for brain death are met. This is the time that should appear on the death certificate as the time of death. Removal of the ventilator at a later time should be seen as the removal of unnecessary machines from a corpse. Although clinicians should be compassionate in the language that they use, they must take care to deliver an accurate and consistent message to the family and emphasize that bodily functions dependent on the brain are being artificially supported and will cease as soon as the machines are stopped. For example, a family could be told, "We tested your son and unfortunately we found that none of his brain is working. That means he is dead. He passed away at 6 o'clock."

### Permission for Autopsy

Physicians may sometimes have the opportunity to discuss the option of an autopsy with the patient or family before death, particularly in situations where death is expected and the patient or family has had an opportunity to reflect on their wishes beforehand. In most cases, however, discussions about autopsy occur within a short time after the patient's death. Because this may coincide with the height of the family's grief, many families may be unable to cope with the

complicated factors that must be considered in making this decision. This problem is compounded by the fact that education about the autopsy procedure is perceived as inadequate in many residency programs, creating the risk of misinforming the family about the nature of the autopsy and possible alternatives. One frequent misconception is that the organs (or most of the organs) are customarily returned to the body after they are examined. Another is that a limited autopsy (percutaneous biopsies or examination of a single organ, for example) is generally an acceptable substitute for a complete autopsy. Even although modern imaging and diagnostic tools have increased the accuracy of premortem diagnosis, complete autopsies continue to provide answers to unresolved clinical questions and frequently reveal major unexpected factors that contributed to the patient's death.

Clinicians must be aware of local regulations that require notification of the medical examiner after death. When required, the medical examiner has authority to perform an autopsy without permission from the family. Clinicians should strive to maintain a supportive relationship with the family by emphasizing the importance and necessity of medicolegal examinations and that the clinical team typically has no influence over the medical examiner's decision. Medical examiners may take religious reasons for opposing an autopsy into account in reaching their decision, but in most jurisdictions they are under no obligation to do so. The medical examiner may not reach a decision concerning an autopsy until several hours after a patient's death. Families should be informed that an evaluation by the medical examiner's office is pending so that they will not be surprised if the medical examiner chooses to perform the autopsy. This is especially important if the family would otherwise decide against having an autopsy performed, because they could feel betrayed if they believed that their wishes were being arbitrarily disregarded. A clinician might say, for example, "We will do everything possible to respect your wishes regarding an autopsy, but you should know that the medical examiner is authorized by law to perform an autopsy, if he or she believes it is important for legal purposes."

## Organ Donation

Current federal regulations require all institutions receiving Medicare or Medicaid funds to have the appropriate individual ask the family of every deceased patient for permission to procure tissues and organs. This discussion should occur separately from notification of the patient's death, and Health Care Financing Administration regulations now require that the request be made by someone specially trained in asking for organ and tissue donation. Critical care practitioners who are interested in making these requests should therefore receive special training. Recently these federal regulations have been revised so that institutions are now required to contact the local organ procurement organization concerning any death or impending death. When appropriate, the organ procurement organization then sends a representative to the hospital to ensure that the family will be approached at the appropriate time by a professional skilled in presenting the option of organ donation and in accurately answering the family's questions and addressing their concerns. Studies have documented that this approach enhances the likelihood that families will be asked to donate and might increase the chance that they choose to donate.

Although families of patients who have been declared brain dead commonly are asked to grant permission for organ donation, patients declared dead by cardiopulmonary criteria (so-called nonheart-beating organ donors) can also sometimes be suitable donors. Nonheart-beating cadavers have always been possible donors of skin, bone, corneas, and heart valves, but recent protocols have expanded the opportunities for some of these patients to donate kidneys, livers, and rarely even lungs and hearts. These solid organ procurements are performed under protocols that call for life-sustaining treatments to be withdrawn (usually mechanical ventilation) under controlled conditions (usually in the operating room), with death declared by cardiac criteria following 2 to 5 min of pulselessness. Alternatively, non-heart-beating organ donation can proceed after a failed attempt at resuscitation. The solid organs then are either removed immediately or preserved in situ by infusing cold organ preservation solution through vascular cannulae before removal. This approach requires strict adherence to many ethical and technical details, and the procedure should never be performed on an ad hoc basis without a prospectively developed institutional protocol.

### Attending Funerals

Opinions about whether clinicians should attend funerals vary widely. Although it would be quite impractical for an intensive care clinician to attend funerals of patients regularly, attendance may be welcome and appropriate when there has been a longstanding relationship between the clinician and the patient or family. Even when there has only been a brief opportunity for the clinicians to become acquainted with the patient or family, family members may feel a profound attachment to the ICU clinicians, perhaps because of the intensity of the ICU experience. Attendance at the funeral in these circumstances may be highly valued by the family and could permit the clinician to release some of the grief and loss that is a part of working with critically ill and dying patients. Striking a balance between the need to maintain a healthy emotional distance from patients and families and yet avoiding a destructive emotional detachment is a difficult yet important challenge for ICU clinicians.

### Bereavement Programs

The responsibilities of intensive care do not end when the patient is taken to the morgue. In addition to the issues about autopsy and organ donation outlined previously, families may need assistance with choosing a funeral home and with making preliminary arrangements for the disposition of the body. If a family has consented to an autopsy, the ICU should ensure that a physician (e.g., an intensivist, a subspecialist, or a primary physician) will notify the family and offer to meet with them as soon as results are available. By explicitly delegating this task to a specific clinician, the chances are reduced that this important follow-up will be overlooked. Specific processes should be in place to ensure rapid response to spiritual and psychological needs, as required by the Joint Commission on Accreditation of Healthcare Organizations. Bereavement programs can be structured to provide follow-up cards or notes to the family at set intervals (usually including the first anniversary) and can include sympathetic comments from nurses and doctors who were involved in the patient's care. Supplemental information such as booklets or bibliographies to provide guidance and contact with support groups also can be provided.

## Special Ethical Issues

### Terminal Sedation

Terminal sedation is a term that has been used to describe the practice of sedating patients to the point of unconsciousness, as a last resort and when all other methods of controlling their suffering have failed. Typically, either benzodiazepines or barbiturates are used as sedatives, although propofol could also be useful for this purpose. Once unconscious, patients typically die of dehydration, starvation, or a complication of the treatment, with death usually occurring within several days.

This approach rarely is needed in the ICU environment, where patients sedated to the point of unconsciousness are generally dependent on mechanical ventilation, with death following the withdrawal of that life-sustaining therapy. Occasionally, however, ICU patients who are not receiving mechanical ventilation will require escalation of analgesics and sedatives to the point of unconsciousness.

Some have argued that terminal sedation is merely a covert form of euthanasia. Once the patient is unconscious, generally no attempt is made to restore the patient to consciousness, and medical nutrition and hydration are terminated. Others have defended terminal sedation under the rule of double effect. In addition, the U.S. Supreme Court implicitly endorsed the practice in two recent decisions concerning physician-assisted suicide, citing the technique as an alternative to physician-assisted suicide that could ensure, at least theoretically, that no patient should die with "untreatable" pain. At least in part because of this legal endorsement, terminal sedation has become more widely practiced, although it remains controversial.

### Treating the Patient vs. Treating the Family

A standard principle in bioethics is that physicians should consider only the patient's best interests and defend those interests against the potentially competing demands of third parties. This view may be a bit naïve. The interests of patients almost always are interwoven with those of family members and other loved ones, and physicians are often in the position of choosing which interests should prevail. This should not be surprising when one considers that family members make sacrifices for one another daily in everyday life; why should it be any different when it comes to making medical decisions? This tendency is especially prominent in pediatrics, where pediatricians commonly see their role as "treating the family," placing the best interests of the child within the context of the family's resources and needs.

Attitudes about the proper role of the family's interests vary widely. Some view the family's wishes primarily as a conflict of interest that needs to be blocked. Others allow the families' wishes to enter into decision-making only with the explicit permission of the patient, whereas others see the patients' interests as being interdependent with those of the family and at times legitimately overridden by the needs of these others.

These issues take on a special significance at the end of life. Because the interests of the patient may be perceived as greatly diminished at this time, clinicians may



be more likely to consider the needs of the family as more important. Consider, for example, the question of whether to perform a tracheostomy and initiate chronic ventilation for a severely demented elderly man who is primarily cared for by his daughter. Perhaps in this circumstance the needs and wishes of the daughter and her family should be considered along with the best interests of the patient.

Similar issues arise in the use of sedatives and analgesics at the end of life. Consider a patient who is near death and having "agonal" respirations. The family finds these very distressing, despite reassurances from the clinicians that the patient is unconscious and not experiencing any pain or suffering. Should the physician administer additional opioid to the patient, with the intention of making the patient appear more peaceful for the benefit of the family? Both of these examples present relatively common dilemmas that are not well addressed by the standard principles and paradigms that currently exist in bioethics.

### The Pharmacologically Paralyzed Patient

Neuromuscular blocking agents (NMBAs) are required occasionally for the management of critically ill patients, primarily to facilitate the use of nonphysiologic ventilatory modes such as inverse ratio ventilation and high-frequency oscillation. When a decision is made to withdraw ventilator support from a patient who is paralyzed by these agents, there is a question as to whether the effects of the medication need to be reversed or allowed to wear off before the ventilator is withdrawn.

This dilemma is not infrequent. For example, three of 33 patients (9%) in one study continued to receive NMBAs during the withdrawal of life support. One survey of physician members of SCCM reported that 6% have used NMBAs at the end of life at least occasionally, whereas another survey of pediatric intensive care specialists in the United Kingdom reported that 12% would continue NMBAs during ventilator withdrawal.

NMBAs possess no sedative or analgesic activity and can provide no comfort to the patient when they are administered at the time of withdrawal of life support. Clinicians cannot plausibly maintain that their intention in administering these agents in these circumstances is to benefit the patient. Indeed, unless the patient is also treated with adequate sedation and analgesia, the NMBAs may mask the signs of acute air hunger associated with ventilator withdrawal, leaving the patient to endure the agony of suffocation in silence and isolation. Although it is true that families may be distressed while observing a dying family member, the best way to relieve their suffering is by reassuring them of the patient's comfort through the use of adequate sedation and analgesia.

The same considerations apply to most patients who are receiving NMBAs at the time that the decision to withdraw life support is made. In most cases, the effect of these agents can be reversed or allowed to wear off within a short period of time, allowing for the withdrawal of mechanical ventilation in the absence of the confounding effects of paralysis. As a general rule, therefore, pharmacologic paralysis should be avoided at the end of life.

Patients who have been receiving NMBA's chronically for management of their ventilatory failure occasionally can present a more difficult ethical dilemma. In some situations, restoration of neuromuscular function may not be possible for several days or even weeks, because of relative overdosage of the drug or the accumulation of active metabolites. When faced with this problem, the clinician must choose between withdrawal of the ventilator while the patient is paralyzed vs. continuation of life support well beyond the point at which the patient and family have determined that the burdens of such treatments outweigh the probable benefits. In this circumstance, it may be preferable to proceed with withdrawal of life support despite the continued presence of neuromuscular blockade. This recommendation is in accord with others who have commented on this issue.

Before proceeding with the withdrawal of life support from a patient who is pharmacologically paralyzed, several issues must be carefully considered. First, the clinicians must be quite certain that the patient is truly dependent on ventilator support for survival. This is not always easy to do - 8% of "terminally weaned" patients from one study survived to hospital discharge. If there is a small but significant chance that the patient could survive separation from the ventilator in the absence of the neuromuscular blockade, then the effects of the blockade must be eliminated before ventilator withdrawal.

Second, clinicians must be aware that neuromuscular blockade will significantly impair their ability to assess the patient's comfort. Paralyzed patients are unable to communicate any evidence of discomfort or distress during the process of withdrawal of life support. Autonomic signs such as hypertension and tachycardia are highly unreliable. The onus is on the clinicians to use medications in dosages sufficient to ensure the patient's comfort despite the absence of the usual behavioral clues to the patient's level of distress. This is certainly possible (it is done routinely by anesthesiologists caring for pharmacologically paralyzed patients during anesthesia and surgery), but it does require sufficient knowledge, skill, and experience on the part of the ICU clinicians.

Third, clinicians must balance the costs of waiting until the NMBA's can be reversed or wear off against the potential benefits. In addition to removing uncertainty about the prognosis and ensuring the availability of behavioral clues about the patient's comfort, waiting until neuromuscular function can be restored has the theoretical benefit of allowing the patient to interact with family members and other loved ones both before and during the process of withdrawing life support.

In summary, in certain cases of prolonged paralysis, it may be reasonable to proceed with removal of the ventilator provided the clinicians a) are highly certain that the patient could not survive separation from the ventilator; b) proceed with careful regard for the patient's comfort; and c) have concluded that the benefits of waiting for the return of neuromuscular function are not sufficient to outweigh the burdens.

#### CLINICAL ALGORITHM(S)

None provided

## EVIDENCE SUPPORTING THE RECOMMENDATIONS

### TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of evidence supporting the recommendations is not specifically stated.

## BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

### POTENTIAL BENEFITS

- Appropriate use of medication and/or technology during end-of-life care
- Decreased distress (e.g., pain, anxiety) and increased comfort for patients, families and caregivers during the end-of-life care process
- Improved satisfaction with end-of-life care

### POTENTIAL HARMS

- Opiates are mu-receptor agonists, and central mu-receptors invoke analgesia, sedation, respiratory depression, constipation, urinary retention, nausea, and euphoria.
- Disadvantages of haloperidol include extrapyramidal symptoms, which are less common when the drug is given intravenously as opposed to enterally. Extrapyramidal symptoms are more common in children reducing the usefulness of this medication in the pediatric population.
- The disadvantages of barbiturates include an absence of analgesic effect, necessitating the concurrent administration of analgesics (e.g., opioids) whenever the patient's symptoms include pain. Barbiturates also have been strongly linked to the practice of euthanasia, having been used for that purpose in the Netherlands and for the execution of prisoners by lethal injection in the United States. Even when appropriately administered within existing guidelines, therefore, their use could be misinterpreted as the practice of euthanasia.

## QUALIFYING STATEMENTS

### QUALIFYING STATEMENTS

Recommendations such as these can only attempt to articulate practices that are based on sound ethical reasoning and that are consonant with current cultural and legal norms.

## IMPLEMENTATION OF THE GUIDELINE

### DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

## INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

### IOM CARE NEED

End of Life Care

### IOM DOMAIN

Effectiveness  
Patient-centeredness

## IDENTIFYING INFORMATION AND AVAILABILITY

### BIBLIOGRAPHIC SOURCE(S)

Truog RD, Cist AF, Brackett SE, Burns JP, Curley MA, Danis M, DeVita MA, Rosenbaum SH, Rothenberg DM, Sprung CL, Webb SA, Wlody GS, Hurford WE. Recommendations for end-of-life care in the intensive care unit: the Ethics Committee of the Society of Critical Care Medicine. Crit Care Med 2001 Dec;29(12):2332-48. [127 references] [PubMed](#)

### ADAPTATION

Not applicable: The guideline was not adapted from another source.

### DATE RELEASED

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### GUIDELINE DEVELOPER(S)

Society of Critical Care Medicine - Professional Association

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### GUIDELINE COMMITTEE

Not stated

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## FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

## GUIDELINE STATUS

This is the current release of the guideline.

## GUIDELINE AVAILABILITY

Electronic copies: Available in Portable Document Format (PDF) from the [Society of Critical Care Medicine \(SCCM\) Web site](#).

Print copies: Available from the Society of Critical Care Medicine, 701 Lee Street, Suite 200, Des Plaines, IL 60016; Phone: (847) 827-6869; Fax: (847) 827-6886; on-line through the [SCCM Bookstore](#).

## AVAILABILITY OF COMPANION DOCUMENTS

None available

## PATIENT RESOURCES

None available

## NGC STATUS

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